Designing Visual Cards for Digital Mental Health Research with Ethnic Minorities

Amid Ayobi, Annali Grimes, Sue Mackinnon, Ewan Soubutts,
Rachel Eardley, Zoe Banks Gross, Rachael Gooberman-Hill, Aisling Ann O'Kane

University of Bristol, Bristol, UK; Knowle West Media Centre, Bristol, UK
{amid.ayobi; e.soubutts; rachel.eardley; r.gooberman-hill; a.okane}@bristol.ac.uk,
{annali.grimes; sue.mackinnon; zoe}@kwmc.org.uk

ABSTRACT

Gaining an understanding of people's diverse mental health needs is essential for informing the design of inclusive mental health technologies. However, conversations about mental health experiences can be challenging for both researchers and participants. We present the design of visual cards that illustrate an inclusive mental health concept to support researchers and participants in understanding and sharing mental health experiences. We illustrate the iterative design of the visual cards with our reflections and feedback from ethnically diverse participants. We found that designing the visual cards fostered insightful reflections within the design team regarding the roles of identity, gender, and ethnicity in designing culturally sensitive content and research. Participants from minority ethnic backgrounds valued the illustrative elements of the visual cards and highlighted the importance of supporting different languages and visual cultures. We discuss use cases for the visual cards and implications for designing culturally sensitive mental health technologies.

DIS '21, June 28-July 2, 2021, Virtual Event, USA
 ACM ISBN 978-1-4503-8476-6/21/06…$15.00
https://doi.org/10.1145/3461778.3462085

Author Keywords

Mental health; ethnic minority; BAME; diversity; cultural sensitivity; cultural competence.

CSS Concepts

• Human-centered computing~Human computer interaction (HCI)~HCI design and evaluation methods~User studies

INTRODUCTION

The global Black Lives Matter movement and COVID-19 pandemic have highlighted that people from minority ethnic backgrounds are disproportionally affected by sociocultural and structural inequalities in managing their mental health [2, 22, 23]. Technologies provide significant potential to transform mental health services and self-care practices outside clinical settings [21]. However, the potential of technologies is intertwined with digital inequalities [23], such as access to technologies and skills of how to mindfully engage in self-care. Mental health technologies that do not meet the needs of ethnic minorities can not only widen sociocultural gaps but also increase digital inequalities.

HCI researchers and UX practitioners apply a wide range of methods, such as interviews, focus groups, and co-design workshops, to gain a detailed understanding of mental health needs as part of human-centred design processes [1, 8, 11, 12, 17, 26-28]. However, eliciting and articulating mental health experiences and needs can be challenging in practice, for both participants and researchers. On the one hand, participants are expected to be able to grasp mental health constructs as part of research processes within a relatively short period of time, including informed consent procedures. However, participants can have diverse levels of prior mental health knowledge and metacognitive capacities to reflect on subjective mental health experiences. For example, Linney et al. [18] have documented varying preferences to share lived experiences of mental illness and diverse views of mental illness management within a Somali community. On the other hand, researchers are typically expected to strike a delicate balance between supporting agency and providing scaffolding during conversations with participants. However, researchers have varied skills to manage power relationships: these asymmetrical power dynamics [4, 15, 32] can make not only participants but also researchers vulnerable [7].

Dialogical approaches [27] and methodological support tools provide significant potential to facilitate conversations between researchers and participants, inform the design of culturally sensitive technologies, and improve research outcomes. Prior work has demonstrated the benefits of methodological tools in different domains [3, 5, 9, 10, 19, 20, 29, 31]. For example, Bekker and Antle [5] present a set of cards to guide the design of technologies for children and Luger et al. [20] present a series of ideation cards to foster discussion on data protection regulations.

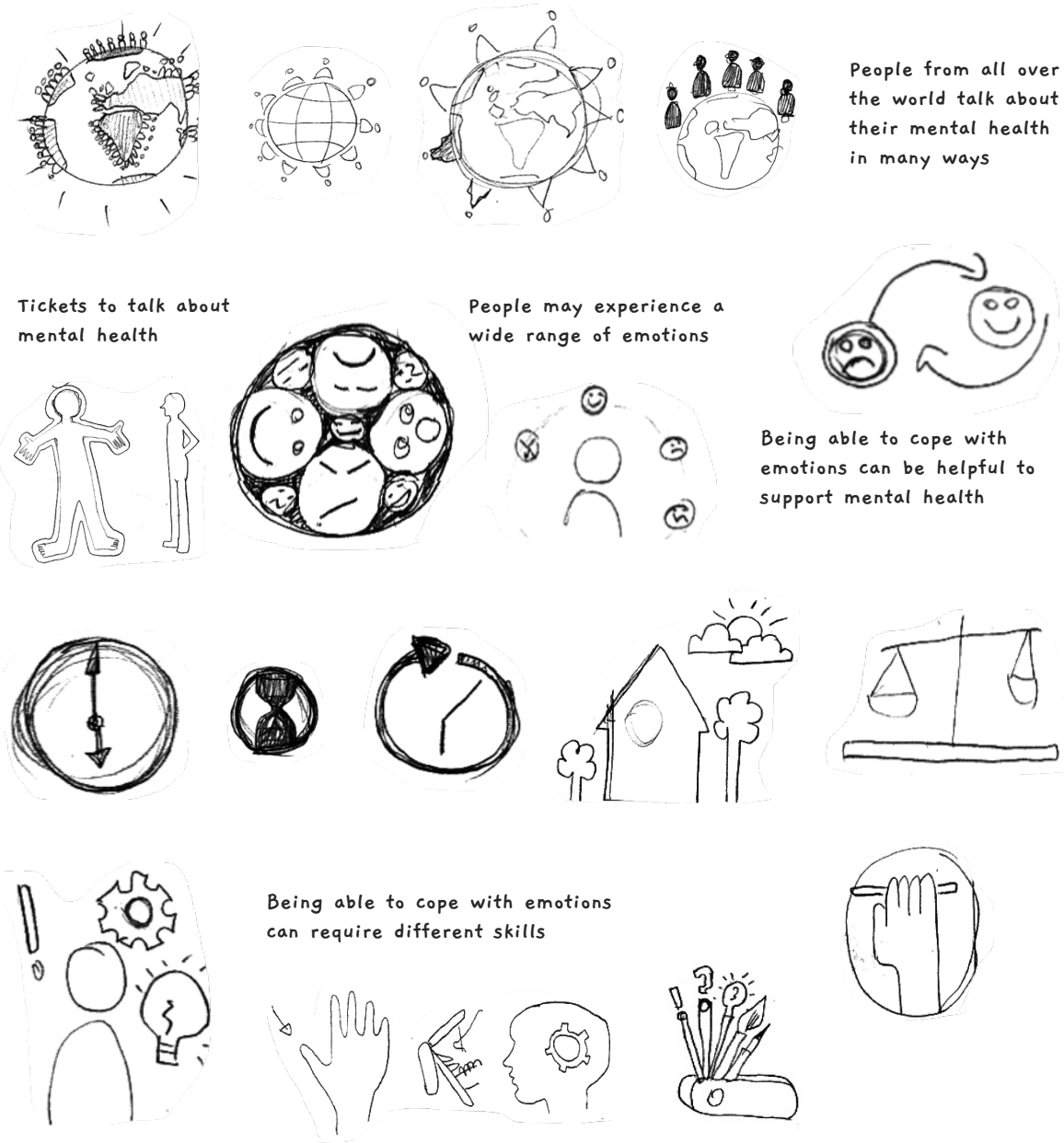
In this pictorial paper, we illustrate the iterative design process of visual cards that draw on an inclusive and holistic mental health concept to support researchers and participants in understanding and sharing mental health views and experiences.

Research and Design Objectives

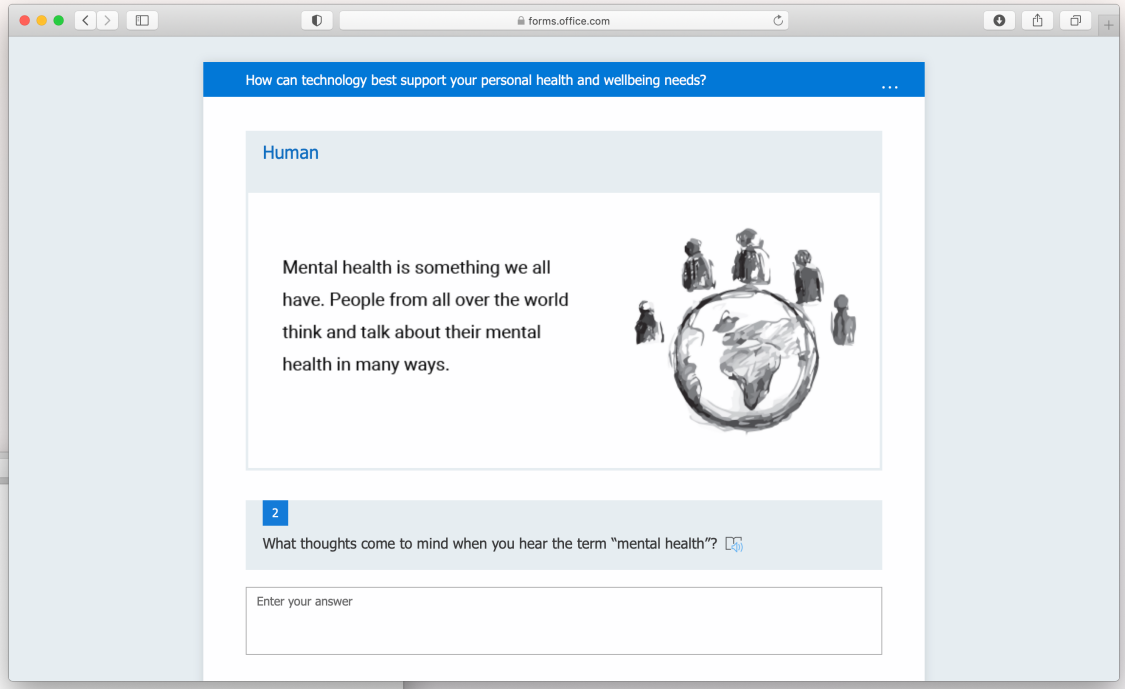
Our objective was to gain a detailed understanding of the mental health needs of local minority ethnic community organisations and their members. We aimed to support transparent and meaningful research experiences based on a shared understanding of what mental health entails. Our multicultural design team comprised HCI researchers and members of a digital arts centre and charity, including an artist and a creative writer.

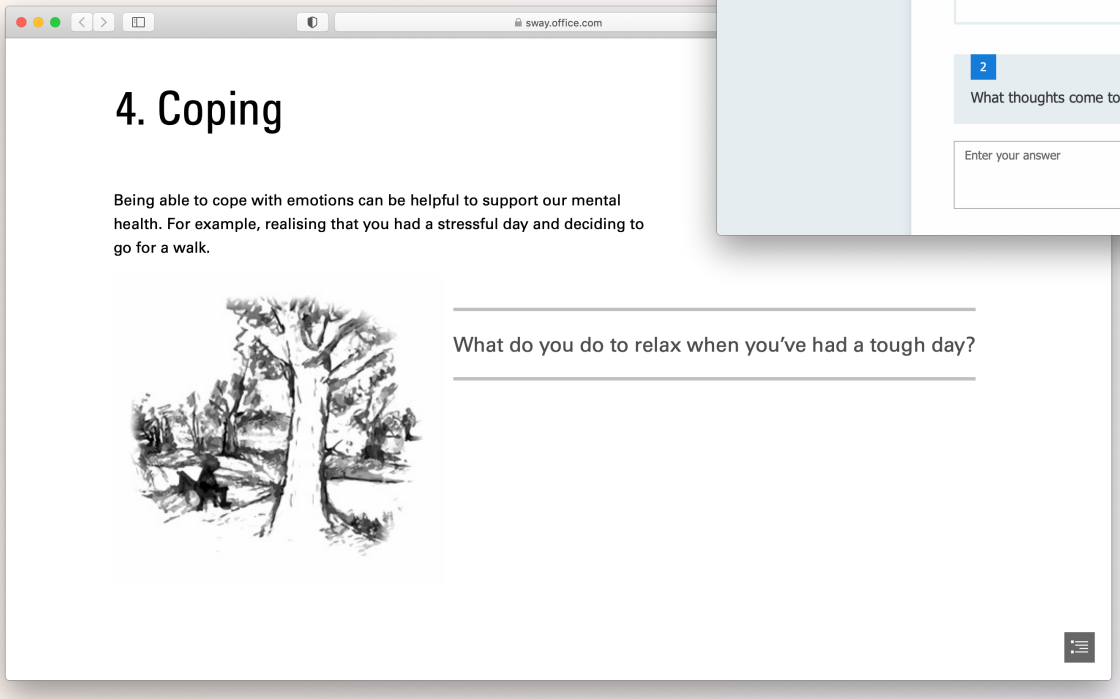
Design Process

Drawing on a human-centred design process, we iteratively designed a set of visual cards. The design of the visual cards does not focus on a specific mental condition, such as depression, but centres on a holistic mental health concept according to Galderisi et al. [14]. The design of the visual cards intends to support researchers and participants in applying bottom-up approaches to identify mental health and technology needs. The visual cards are composed of three parts: (1) descriptions to explain aspects of mental health; (2) illustrations to visualise the mental health descriptions; and (3) open-ended questions to foster reflections on mental health views and experiences. Due to the COVID-19 pandemic, we used a website to present the visual cards and conducted phone interviews with 11 participants to receive feedback. Interview questions covered participants' perceptions of the visual cards and suggestions for improvement. For example, P2 explained that the text of the visual cards could be easily translated based on her prior work experience as a translator. P7 proposed to colour in illustrations to create a more positive look and feel. Interviews were audio recorded and thematically analysed [6]. A summary of findings was shared within the design team after each interview to iteratively inform the design of the visual cards.



The first evaluation phase involved three employees of local ethnic minority organisations. P1 described their ethnic background as Asian and reported working with different local multi-ethnic community organisations. P2 described their ethnic background as African working for a multicultural refugee organisation. P3 described their ethnic background as Asian and explained supporting a South Asian community that focused on the wellbeing of older adults. Future research will involve community-driven studies based on the visual cards with P1-P3.





During the second evaluation phase, we explored the visual cards with members of an online community aimed for people from diverse ethnic backgrounds (P4-P11). The community was formed as a response to the global Black Lives Matter movement with the intention to provide a shared and safe place for employees from diverse ethnic backgrounds. Three participants described their ethnic background as Black African; three as mixed (Black/British, White/Chinese, Indo Mauritian); and two as Chinese.

Inspired by an inclusive definition of mental health [14] and in collaboration with a creative writer, we have iteratively developed six themes to explain what mental health entails. These descriptions informed the design of visual cards, including illustrations and open-ended questions to elicit mental health views and experiences.

Emotions

Mentally healthy people may experience a wide range of emotions: from happiness and excitement to anger and fear. Our emotions can change over a period of time.

Human

Mental health is something we all have. People from all over the world think and talk about their mental health in many ways.

Coping

Being able to cope with emotions can be helpful to support your mental health. For example, realising that you had a stressful day and deciding to go for a walk.

What does mental health entail?

"Mental health is a dynamic state of internal equilibrium which enables individuals to use their abilities in harmony with universal values of society. Basic cognitive and social skills; ability to recognize, express and modulate one's own emotions, as well as empathize with others; flexibility and ability to cope with adverse life events and function in social roles; and harmonious relationship between body and mind represent important components of mental health which contribute, to varying degrees, to the state of internal equilibrium." [14]

Environment

The world around us may influence our emotions: our family, friends and work as well as food, the weather, and illness.

Mental Illness

If life events cause distress or trauma, people may develop mental illnesses. Mental illnesses can seriously affect people's family, work and social lives. Anxiety disorder and depression are examples of common mental illnesses.

Support

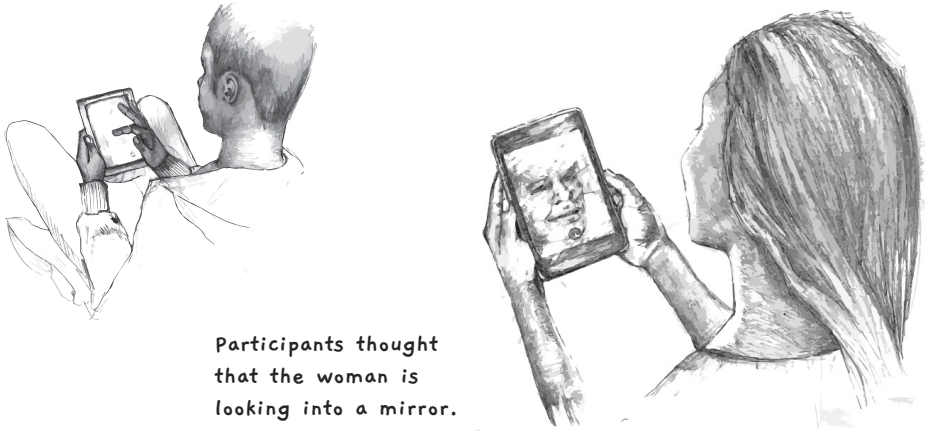
Our abilities, such as being able to take care of a child or go to work, can influence our mental health. Sometimes we may need support to live a mentally healthy life.

Towards a Realistic Visual Style

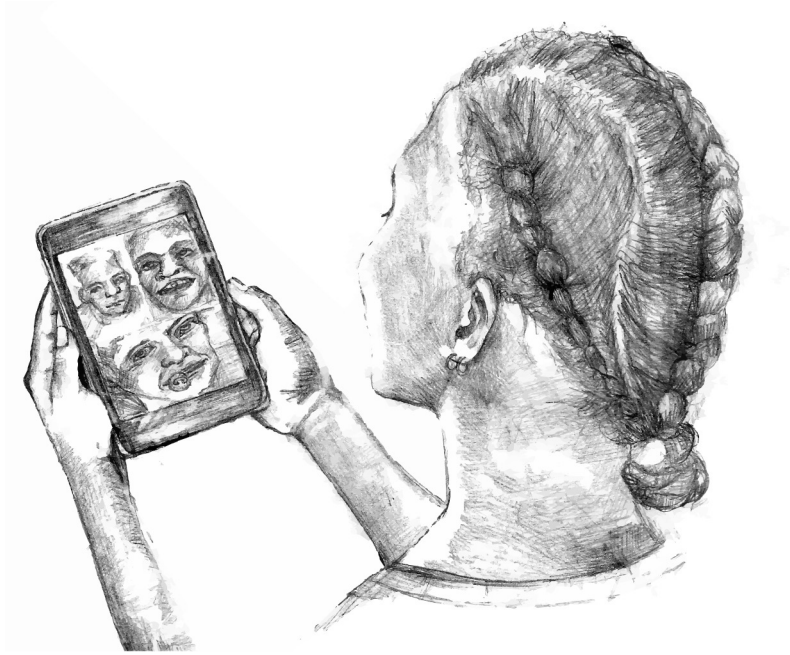
Initially, we applied an abstract visual style not only because we aimed to explore a range of variations but also because it was unclear to us how we could appropriately illustrate people from diverse ethnic backgrounds. At later stages of the design process we transitioned towards a more realistic visual style as we learned more about our potential participants, studied local minority ethnic community leaflets with photos, received feedback on illustrations, and gained confidence in portraying people from diverse ethnic backgrounds over time.

We transitioned towards a more realistic visual style since participants faced challenges to recognise cultural diversity in our initial abstract illustrations. Our objective was to find a visual language that is respectful and non-judgmental. Looking at photo-graphic representations of real people helped manage our own preconceptions.

Lifestyles as Cultural Cues



Participants thought that the woman is looking into a mirror.



The third iteration shows clearer how a woman is having a video call.

Hairstyles as Cultural Cues

These illustrations intend to help elicit reflections on technology usage and mental health and document shifts regarding gender and hairstyles. The illustrations particularly fostered discussion about the role of our gender and ethnic identity as designers. For example, the creator of the illustrations explained that the transition away from a woman with straight hair documents her tendency to draw images that might be interpreted as of white women. We engaged with the history, oppression, and sociocultural meaning of natural hairstyles [24] to inform our design work.

Cultural Appropriation and Cultural Appreciation

The design of the illustrations was a self-reflective learning process that encouraged us to discuss cases of cultural appropriation and cultural appreciation. For example, an HCI researcher explained that football players like David Beckham and Zé Roberto inspired him to have braids as a teenager. The discourse on cultural appropriation focuses attention to understanding inequalities and harmful consequences of adopting elements of a non-dominant culture. We collaborated with colleagues and participants from minority ethnic backgrounds to respectfully draw on diverse visual cultures.

Objects of Daily Use as Cultural Cues

We created this series of illustrations to capture reflections on coping strategies. However, we found that the cultural cues and ambiguity caused some concern and confusion. Feedback suggested that the teacup and saucer can be perceived as strong references to the British tea culture, which encouraged us to learn more about drinking cultures across the world [30].

The next iteration is refined showing a woman holding a mug in her hands. Our intention of depicting a mug instead of a teacup was to expand the interpretation space: the actor might have a hot drink, such as tea, coffee, chocolate, or milk.

In the third illustration the lady is wearing a head covering. Feedback suggested that the identity of the woman was unclear. Viewers associated South Asian and Slavic cultures and lower social statuses with the illustration. We abandoned this illustration as its ambiguity seemed to support unintended stereotypes.

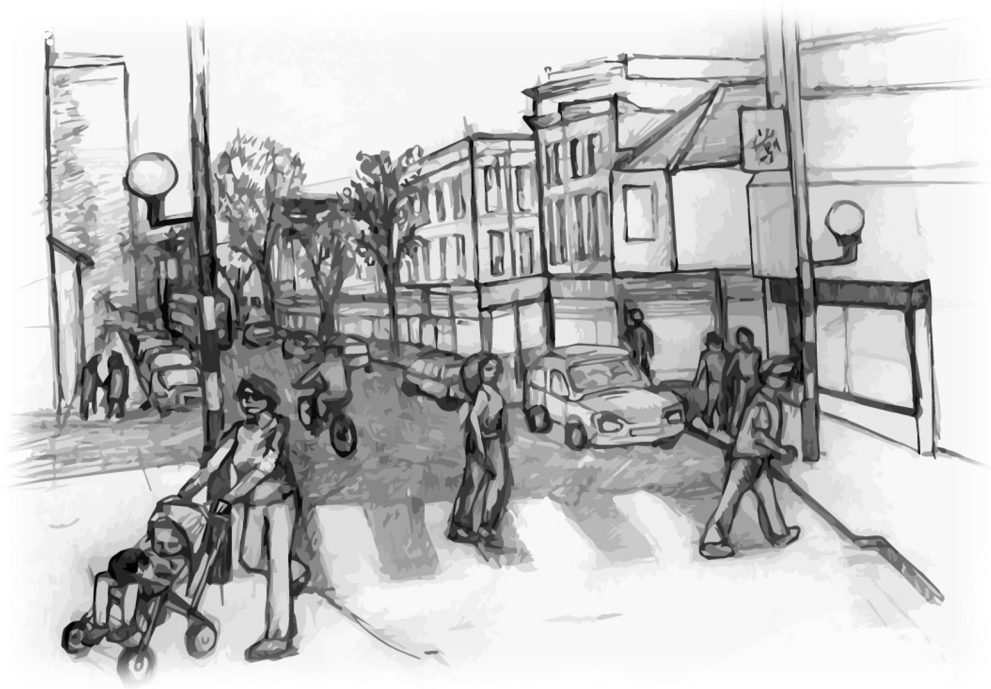
Norms, Gender and Idioms

Depicting a person or user of a technology with simple geometrical shapes is a common design practice. However, we found that this visual system does not necessarily translate to non-designers. Participants associated, for example, dementors (i.e. soul-less fantasy creatures) with this illustration.

This illustrations aimed to visualise a wide range of emotions that a person can experience over time. A female participants highlighted that "there are no women!"- which encouraged us to review the gender representation of the visual cards.

We drew on the idiom “carrying the weight of the world on one's shoulders" to inform the visual card regarding mental illness. We found that two participants were not familiar with the idiom, however, they explained that the visual re-presentation supported the intended message.

Subjective Perceptions and Needs



Here we see illustrations that show two contrasting sceneries. On the one hand, there is an illustrations of a local park depicting a peaceful environment. On the other, we used a local urban environments as a contrasting metaphor, to support reflections on environmental factors that could potentially influence people's mental health in negative ways.

We found that participants have subjective perceptions of different environments and individual coping strategies: from taking a bath to going for walks in pairs depending on personal living circumstances. We considered different directions, such as supporting participants to choose visual cards that depicted a range of potential stressors and coping strategies.

Tickets to Talk about Mental Health

1. Human

Mental health is something we all have. People from all over the world think and talk about their mental health in many ways.

2. Emotions

We experience a wide range of emotions: from happiness to fear. Our emotions can change over time.

3. Environment

The world around us may influence our emotions: our family, friends and work as well as food, the weather and illness.

The “tickets to talk about mental health” could be used as part of interviews and design workshops. There are seven pairs of tickets. Each pair comprises one ticket that introduces a mental health topic and one ticket that displays open-ended questions to foster reflections and conversations.

1. Human

What thoughts come to mind when you hear the term mental health?

Can you imagine what your family and friends think about the topic mental health?

2. Emotions

What does your typical week-day look like?

How do you feel during a typical weekday?

3. Environment

What kind of things in the world around you bring you joy?

What kind of things in the world around you make you feel uncomfortable?

Researchers could, for example, present the tickets on a table so that participants can choose topics they want to talk about. This set of visual cards illustrate one possible visual design concept. Researchers and practitioners could reuse and adapt the illustrations and questions according to their needs (Please contact the authors if you would like to receive the most recent versions of the visual cards).

Tickets to Talk about Mental Health

4. Coping

Being able to cope with emotions can be helpful: for example, realising that you had a stressful day and deciding to go for a walk.

5. Support

Our abilities, such as being able to take care of a child or go to work, can influence our mental health. Sometimes we may need support.

6. Mental Illness

If life events cause distress, people may develop mental illnesses, such as depression. Mental illnesses can seriously affect people's family, work and social lives.

7. Technology

There are many different types of technology - such as laptops, smartphones and tablets. Technology can can affect our mental health.

4. Coping

What do you do when you've had a tough day?

What advice would you offer a friend who had a tough day?

5. Support

Can you think of any situations in which you were happy about getting support?

Can you think of any day-to-day challenges that you wish you had support for?

6. Mental Illness

What do you think when you hear the term mental illness?

What do people in your social circle think about mental illness?

7. Technology

What are your favourite technologies?

Are there any technologies that you avoid?

DISCUSSION

People from minority ethnic backgrounds are disproportionally affected by sociocultural and structural inequalities in managing their mental health, including stigma, inaccessible technologies, and exclusionary mental health services [1, 2, 23]. Through joining local events and arranging meetings, we have learned that raising awareness of mental health and challenging metal health stigma were key priorities of local minority ethnic community organisations in Bristol, UK. However, mental health is a complex notion and best practice guidance around conducting technology focused mental health research with people from minority ethnic backgrounds is not well established. We asked: how can we conduct culturally sensitive research to understand the mental health needs of local minority ethnic community organisations and their members? How can we support participants in sharing their mental health views and experiences as part of qualitative research and design studies?

We engaged in a human-centred design process of visual cards that aimed to support both researchers and participants in sharing and understanding mental health experiences. We aimed to support transparent and meaningful research experiences based on a shared understanding of what mental health entails, considering that prior work has documented varied mental health views and stigma in a local minority ethnic community [16]. Here, we outline how the design process of the visual cards supported us in gaining cultural awareness and discuss what the implications for conducting culturally sensitive digital mental health research are.

Gaining Cultural Sensitivity through Design

We felt that the iterative design process of the visual cards helped us not only to explore a support system for conducting research but also to gain cultural awareness and improve cultural competence [13, 16]. Initially we experienced uncertainty portraying visual cultures that were new to us and, what is more, realised our biases in (mis)representing people from different minority ethnic backgrounds. How could we illustrate an individual from a minority ethnic background without knowledge of their culture and lived experience? Unbalanced gender and ethnicity representations in our design work fostered discussion on potential contributing factors and countermeasures. For example, we reflected on what colours we typically use to illustrate humans and how we teach our children to colour in humans with bright skin tones. We gradually gained confidence in depicting different cultures through engaging with literature and particularly through sharing design concepts and receiving feedback from people from diverse minority ethnic backgrounds, including colleagues, community organisation workers, and local activists. In doing so, we have learned about aspects of visualising diverse cultures, including lifestyles (e.g. drinking tea), hairstyles (e.g. braids), and head covering traditions (e.g. hijab). A visual calendar documenting social activities of a South Asian community provided inspiration when going through shifts from abstract to more realistic representations of ethnically diverse people. However, it has become clear that our understanding of diverse minority ethnic cultures was subjective and limited. Gaining cultural sensitivity and competence is an ongoing and participatory learning process that needs to go beyond the representation of people from diverse backgrounds as part of a research project.

Designing for ethnically diverse participants fostered discussion on terminology conventions in the UK, such as “ethnic minorities” and “BAME” (Black, Asian, and minority ethnic). While the UK government draws on the former, the latter acronym is widely used in academic settings while being rejected by some people from minority ethnic backgrounds. Discussions about the acceptability of collecting demographic data with predefined categories have led to the decision to draw on a voluntary open-ended question as part of this exploratory design study (i.e. “How would you describe your ethnic background?”). Furthermore, we learned about the importance of supporting different languages, providing paper-based research materials to those who do not have access or capacity to engage with technology, appreciating the diversity within a multi-cultural community, and reimbursing community organisations members for their help.

Limitations and Future Work

We drew on a human-centred design process and our design team was multidisciplinary and multicultural. The design of the visual cards involved team members from a digital arts centre, that supports people with diverse backgrounds to make positive changes in their lives and local communities. However, it should be considered that our design work has significant limitations. We applied an iterative user-centred design approach that was driven by evaluations with colleagues, community activists, and people recruited from a diverse online minority ethnic community. What is more, we found that representing diverse visual cultures requires not only knowledge of different cultures but also co-creation. We believe that participatory design approaches [11, 17, 25] could be particularly suitable to design support systems for conducting culturally sensitive research and informing the design of inclusive technologies in partnership with a local minority ethnic community organisation and its members. In this way, co-designers from minority ethnic backgrounds could drive design directions and decisions.

We have illustrated the on-going design prosses of a series of visual cards. The design of the visual cards can be adapted to different printable and digital formats and translated into different languages. Furthermore, empirical studies could identify the perceived benefits and limitations of the visual cards in different mental health research settings. Potential use cases include the design of self-care technologies and research methods, such as interview studies, focus groups, and design workshops, where researchers and participants could draw on the visual cards to support conversations about mental health views and experiences.

ACKNOWLEDGEMENTS

Many thanks to all participants, the SPHERE team, and our reviewers for providing insightful feedback on earlier versions of this pictorial paper. This work was performed under the SPHERE Next Steps Project funded by the UK Engineering and Physical Sciences Research Council (EPSRC), Grant EP/R005273/1.

REFERENCES

[1] Adkins, E.C. et al. 2017. Exploring the potential of technology-based mental health services for homeless youth: A qualitative study. Psychological services. 14, 2 (2017), 238.

[2] Ahmed, M.H. 2020. Black and Minority Ethnic (BAME) Alliance Against COVID-19: One Step Forward. Journal of Racial and Ethnic Health Disparities. 7, 5 (Oct. 2020), 822–828. DOI:https://doi.org/10.1007/s40615-020-00837-0.

[3] Alkhuzai, K. and Denisova, A. 2021. Evaluating the Use of Persuasive Design Cards for Novice Designers. Journal of Usability Studies. 16, 2 (2021)

[4] Anyan, F. 2013. The Influence of Power Shifts in Data Collection and Analysis Stages: A Focus on Qualitative Research Interview. Qualitative Report. 18, (2013), 36.

[5] Bekker, T. and Antle, A.N. 2011. Developmentally situated design (DSD) making theoretical knowledge accessible to designers of children's technology. Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (2011), 2531–2540.

[6] Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. Qualitative Research in Psychology. 3, 2 (Jan. 2006), 77–101. DOI:https://doi.org/10.1191/1478088706qp063oa.

[7] Cotterill, P. 1992. Interviewing women: Issues of frienship, vulnerability, and power. Women's Studies International Forum (1992), 593–606.

[8] Davis, H. and Waycott, J. 2015. Ethical Encounters: HCI Research in Sensitive and Complex Settings. Proceedings of the Annual Meeting of the Australian Special Interest Group for Computer Human Interaction (New York, NY, USA, Dec. 2015), 667–669.

[9] Deng, Y. et al. 2014. Tango cards: a card-based design tool for informing the design of tangible learning games. Proceedings of the 2014 conference on Designing interactive systems (2014), 695–704.

[10] Dibitonto, M. et al. 2018. The IoT Design Deck: A Tool for the Co-design of Connected Products. Advances in Usability and User Experience (Cham, 2018), 217–227.

[11] Duarte, A.M.B. et al. 2018. Participatory Design and Participatory Research: An HCI Case Study with Young Forced Migrants. ACM Transactions on Computer-Human Interaction. 25, 1 (Feb. 2018), 3:1-3:39. DOI:https://doi.org/10.1145/3145472.

[12] Ertl, T. et al. 2020. Psychosocial ICT: The Potential, Challenges and Benefits of Self-help Tools for Refugees with Negative Mental Stress. (2020). DOI:https://doi.org/10.18420/ecscw2020_ep11.

[13] Foronda, C.L. 2008. A Concept Analysis of Cultural Sensitivity. Journal of Transcultural Nursing. 19, 3 (Jul. 2008), 207–212. DOI:https://doi.org/10.1177/1043659608317093.

[14] Galderisi, S. et al. 2015. Toward a new definition of mental health. World Psychiatry. 14, 2 (Jun. 2015), 231–233. DOI:https://doi.org/10.1002/wps.20231.

[15] Jagtap, S. 2021. Co-design with marginalised people: designers' perceptions of barriers and enablers. CoDesign. 0, 0 (Feb. 2021), 1–24. DOI:https://doi.org/10.1080/15710882.2021.1883065.

[16] Kirmayer, L.J. 2012. Rethinking cultural competence. Transcultural Psychiatry. 49, 2 (Apr. 2012), 149–164. DOI:https://doi.org/10.1177/1363461512444673.

[17] Knifton, L. et al. 2010. Community conversation: addressing mental health stigma with ethnic minority communities. Social Psychiatry and Psychiatric Epidemiology. 45, 4 (Apr. 2010), 497–504.

[18] Linney, C. et al. 2020. "Crazy person is crazy person. It doesn't differentiate": an exploration into Somali views of mental health and access to healthcare in an established UK Somali community. International Journal for Equity in Health. 19, 1 (Dec. 2020), 190. DOI:https://doi.org/10.1186/s12939-020-01295-0.

[19] Logler, N. et al. 2018. Metaphor cards: A how-to-guide for making and using a generative metaphorical design toolkit. Proceedings of the 2018 Designing Interactive Systems Conference (2018), 1373–1386.

[20] Luger, E. et al. 2015. Playing the Legal Card: Using Ideation Cards to Raise Data Protection Issues within the Design Process. Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15 (Seoul, Republic of Korea, 2015), 457–466.

[21] Nunes, F. et al. 2015. Self-Care Technologies in HCI: Trends, Tensions, and Opportunities. ACM Trans. Comput.-Hum. Interact. 22, 6 (Dec. 2015), 33:1-33:45. DOI:https://doi.org/10.1145/2803173.

[22] Pfefferbaum, B. and North, C.S. 2020. Mental Health and the Covid-19 Pandemic. New England Journal of Medicine. 383, 6 (2020), 510–512. DOI:https://doi.org/10.1056/NEJMp2008017.

[23] Robinson, L. et al. 2015. Digital inequalities and why they matter. Information, Communication & Society. 18, 5 (May 2015), 569–582. DOI:https://doi.org/10.1080/1369118X.2015.1012532.

[24] Rodriguez, C. 2003. Hair story: Untangling the roots of black hair in America. Transforming Anthropology. 11, 2 (2003), 64–65.

[25] Schneider, H. et al. 2018. Empowerment in HCI - A Survey and Framework. Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (New York, NY, USA, 2018), 244:1-244:14.

[26] Tachtler, F. et al. 2020. Supporting the Supporters of Unaccompanied Migrant Youth: Designing for Social-ecological Resilience. Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (New York, NY, USA, Apr. 2020), 1–14.

[27] Talhouk, R. et al. 2019. Involving Syrian Refugees in Design Research: Lessons Learnt from the Field. Proceedings of the 2019 on Designing Interactive Systems Conference (New York, NY, USA, Jun. 2019), 1583–1594.

[28] Talhouk, R. et al. 2019. Refugees & HCI SIG: Situating HCI Within Humanitarian Research. Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems (New York, NY, USA, May 2019), 1–4.

[29] Urquhart, L.D. and Craigon, P.J. 2021. The Moral-IT Deck: a tool for ethics by design. Journal of Responsible Innovation. (2021), 1–33.

[30] Wang, N. 2011. A comparison of Chinese and British tea culture. Asian Culture and History. 3, 2 (2011), 13.

[31] Wetzel, R. et al. 2017. Developing ideation cards for mixed reality game design. Transactions of the Digital Games Research Association. 3, 2 (2017).

[32] Zhang, L.E. and Guttormsen, D.S. 2016. 'Multiculturality'as a key methodological challenge during in-depth interviewing in international business research. Cross Cultural & Strategic Management. (2016).